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## General and health-related Internet use among an urban, community-based sample of HIV-positive women: implications for intervention development

Oni J. Blackstock<sup>a,\*</sup>, Lorlette J. Haughton<sup>a</sup>, Ruby Y. Garner<sup>b</sup>, Keith J. Horvath<sup>c</sup>, Chris Norwood<sup>b</sup>, and Chinazo O. Cunningham<sup>a</sup>

<sup>a</sup>Montefiore Medical Center/Albert Einstein College of Medicine, Department of Medicine, Bronx, NY, USA

<sup>b</sup>Health People: Community Preventive Health Institute, Bronx, NY, USA

<sup>c</sup>Division of Epidemiology & Community Health, University of Minnesota, Minneapolis, MN, USA

### Abstract

Internet-based HIV interventions are increasingly common, although little focus has been on HIV-positive women. To understand the feasibility of using the Internet to deliver behavioral interventions to HIV-positive women, we sought to describe patterns of Internet use for general and health-related purposes and to explore differences between Internet-using and non-using women. From February 2014 to April 2014, 103 women were recruited at six community-based organizations in the Bronx, NY that provide services to HIV-positive persons. Women completed a 30-minute interview and answered a brief survey of socio-demographic factors, risk behavior and clinical characteristics. We performed  $\chi^2$  and Kruskal-Wallis tests to compare Internet users and non-users. Sixty-one percent of participants were current Internet users, most of whom used a personal electronic device (e.g., cellphone/smartphone) to access the Internet. While higher proportions of Internet users were passively engaged (e.g., signed up to receive email updates [42.9%] or watched an online video [58.7%] for health-related purposes), smaller proportions (12.7–15.9%) were involved in more interactive activities such as posting comments, questions, or information about health-related issues in an online discussion or a blog. A majority of Internet non-users (60.0%) expressed interest in going online. Lack of computer or Internet access (37.5%) and Internet navigation skills (37.5%) were the primary reasons for non-use. Compared with non-users, Internet users were more likely to be younger, to have higher socioeconomic status, and to report low health-related social support. Despite having a lower proportion of Internet users in our study than the general population, Internet-using women in our study had relatively high levels of online engagement and went online for both general and health-related purposes. However, Internet-based interventions targeting HIV-positive women will likely need to include providing computer and/or Internet access as well as training participants in how to navigate the Internet.

## Keywords

HIV; women; Internet; technology; intervention

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## Introduction

Although HIV-positive women in the USA are living longer (Harrison, Song, & Zhang, 2010), many continue to face barriers to engaging in HIV medical care (Aziz & Smith, 2011), and, therefore, are not receiving the full benefits of HIV treatment. It is estimated that only one-quarter of HIV-positive women receive antiretroviral therapy *and* are virally suppressed (Centers for Disease Control and Prevention [CDC], 2012). Given these persistent gaps in care, innovative strategies are needed to engage women throughout the HIV care continuum.

Internet interventions have been defined as “systematic treatment/prevention programs, usually addressing one or more determinants of health ... delivered largely via the Internet ... and interfacing with an end user” (Bennett & Glasgow, 2009). However, concerns regarding disparities in Internet use, especially among poor and minority groups persist (Zickuhr & Smith, 2012). For example, while only 62% of those with an annual household income below \$30,000 use the Internet, 97% with an annual household income of \$75,000 or higher are Internet users (Zickuhr & Smith, 2012). The growth of mobile devices (e.g., smartphones) with Internet access may serve to decrease disparities in Internet access and use in the USA (Zickuhr & Smith, 2012). Additionally, prior research has shown that Internet use is common among HIV-positive persons in the USA (Mayben & Giordano, 2007; Thomas & Shuter, 2010), paralleling trends seen in the broader USA population (Brenner & Smith, 2013). Online interventions have been increasingly used to deliver HIV-related primary prevention (Adam et al., 2011; Bull, Pratte, Whitesell, Rietmeijer, & McFarlane, 2009; Danielson et al., 2013; Hightow-Weidman et al., 2012; Hirshfield et al., 2012; Rhodes et al., 2011; Rosser et al., 2010; Young et al., 2013) and secondary prevention (Horvath et al., 2013; Marhefka et al., 2013; Shegog, Markham, Leonard, Bui, & Paul, 2012) interventions and have focused on providing education, risk reduction skills training, and/or peer support to promote behavior change. However, with one exception (Marhefka et al., 2013), all have targeted either adolescents and/or men who have sex with men.

Given the Internet’s ability to reach patients beyond clinical settings and foster social networks, it is increasingly used as a social support tool among persons with various chronic health conditions, including HIV/AIDS (Beaudoin & Tao, 2007; Horvath et al., 2013; Smedema & McKenzie, 2010; Suls, Bunde, Martin, & Barnett, 2006). Studies show that higher social support is associated with lower levels of HIV-related stigma and higher antiretroviral adherence (Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006; Vanable, Carey, Blair, & Littlewood, 2006; Vyavaharkar et al., 2007). Among HIV-positive persons, Internet use for obtaining health-related information is associated with greater social support, active coping, and antiretroviral adherence (Kalichman et al., 2003; Kalichman et al., 2005).

Although Internet-based interventions have shown success in promoting behavior change, they have been understudied among HIV-positive women, many of whom have limited socioeconomic resources (Aziz & Smith, 2011). Moreover, data on HIV-positive women's patterns of Internet use is limited. To gain a greater understanding of the feasibility of the Internet to deliver interventions to HIV-positive women, we conducted this study 1) to describe patterns of Internet use for general and health-related purposes and 2) to explore differences between Internet users and non-users among an urban, community-based sample of HIV-positive women.

## Methods

### Setting and participants

Women were recruited from February to April 2014 at six community-based organizations (CBOs) in the Bronx, NY that provide social and/or clinical services to HIV-positive persons. Potential participants were approached in the waiting areas of the CBOs and provided information about the study. Eligibility criteria included women who were (1) HIV-positive, (2) English-proficient, and (3) at least 18 years old. Study activities were approved by the Albert Einstein College of Medicine Institutional Review Board.

### Procedures

Interviews occurred in a private room at participating CBOs and took between 30 and 45 minutes. Written informed consent was obtained from participants. Audio Computer-assisted Self-interview was used to collect information from participants. At the conclusion of the survey, women were compensated \$25 and a roundtrip Metrocard (value \$5.00) for their time.

### Measures

**Internet use**—We assessed *current* Internet use for general and health-related purposes using publicly available survey questions from the Pew Internet research project (<http://pewinternet.org>). Internet use was defined by participants' responses to the following question: "Do you ever use the Internet or email?" (Brenner & Smith, 2013). Those who selected "yes" were categorized as "*current* Internet users" and those who answered "no" were categorized as "Internet non-users."

Among Internet users, we collected information about frequency of going online, electronic device ownership (e.g., cellphone/smartphone, desktop computer), how the Internet was accessed, and uses of the Internet (e.g., for email). Internet knowledge was assessed using four questions from the iKNOW scale (e.g., knowledge of Internet terms, fixing Internet-related problems, helping others learn how to use the Internet, and changing Internet settings; Potosky, 2007). Responses to the iKNOW scale are on a 6-point Likert scale and were dichotomized agree/strongly agree vs. all other responses.

Women were asked if they had ever engaged in any of the following online health-seeking behaviors: (1) use a social networking site to obtain health information, (2) start or join a health-related group, (3) follow friend's health-related updates, (4) sign up to receive email

updates about health or medical issues, (5) read about or watch videos about health or medical issues, (6) go online to find others with similar health concerns; and (7) post comments, questions, or information about health issues to online sites. We also asked women if they were ever helped or harmed from information found online. Electronic health literacy was measured using the eHEALS scale, which asks about knowledge of online health resources including where to locate them, how to find them, how to use information once obtained, and comfort with assessing the quality of online health information (Norman & Skinner, 2006). Responses to the eHEALS scale are on a 5-point Likert scale and were dichotomized as agree/strongly agree vs. all other responses.

Internet non-users were asked to report whether there were Internet users in their household, any previous Internet use, interest in using the Internet, asking others for assistance with using the Internet, and their primary reasons for not going online.

**Socio-demographic, risk behavior, and clinical characteristics**—Socio-demographic characteristics included age; race/ ethnicity (non-Hispanic Black, Hispanic, Multiracial/ Other); relationship status (single, married/partnered); level of education completed (less than high school, high school or higher); housing status (own home or apartment, unstably housed or homeless [someone else's home/supportive housing/shelter]); primary caregiver (yes, no); and health insurance (yes, no). Risk behavior characteristics included any high-risk sexual behaviors in the last 30 days (defined as unprotected [i.e., condom-less] non-transactional or transactional vaginal or anal intercourse; yes, no); HIV Risk-taking behavior scale; Darke, Hall, Heather, Ward, & Wodak, 1991); and any drug-related risk behaviors in the last 30 days (defined as using any illicit drugs; yes, no) (Addiction Severity Index) (McLellan, Luborsky, Woody, & O'Brien, 1980). Clinical characteristics included health status (fair/poor, excellent/very good/good); any chronic medical condition (other than HIV) (such as diabetes mellitus, high blood pressure, asthma, heart disease, cancer, hepatitis C, etc.) (yes, no); depression (Center for Epidemiologic Studies Short Depression Scale score  $\geq 10$ ; yes, no) (Cole, Rabin, Smith, & Kaufman, 2004); time since HIV diagnosis; place of HIV medical care (health center or clinic, health care for the homeless/methadone maintenance treatment program/provider visits patient);  $\geq 1$  HIV medical care visit in the last 6 months (yes, no); and antiretroviral adherence (defined as self-report of taking 100% of prescribed doses in the last 30 days) (adherent, non-adherent) (visual analog scale). Health-related social support (Modified Medical Outcomes Study Social Support Survey) (Moser, Stuck, Silliman, Ganz, & Clough-Gurr, 2012) and HIV-related stigma (abbreviated Berger Scale) (Wright, Naar-King, Lam, Templin, & Frey, 2007) were dichotomized as low or high using a median split.

## Analysis

We calculated medians and frequencies for continuous and categorical variables, respectively. For the iKNOW and eHEALS scales, we present the proportions of participants responding agree or strongly agree to each item. Differences in characteristics between Internet users and non-users were assessed using  $\chi^2$  and Kruskal-Wallis tests. We considered p-values of less than 0.05 statistically significant. Statistical analyses were performed using SAS 9.2 (SAS Institute, Inc., Cary, North Carolina).

## Results

### Overall sample characteristics

All eligible participants who were approached completed the survey ( $n = 103$ ). The median age for the sample was 50 years old and most women were non-Hispanic Black (Table 1). Approximately half (46.6%) of women had less than a high school education and were unstably housed (46.4%). Three-quarters (76.7%) reported at least one other chronic medical condition and one-quarter (23.3%) stated that they were in fair or poor health. Forty-percent reported recent high-risk sexual behavior, with a similar proportion reporting recent illicit drug use. Most were prescribed antiretroviral medications (89.3%), and, of those, about two-thirds (68.1%) reported being adherent.

### General Internet, cell phone, and social media use among Internet users

Sixty-one percent ( $n = 63$ ) of women were current Internet users. Among Internet-using women, most went online daily (46.0%) or several times a week (17.5%; Table 2). Most women owned a cellphone (87.3%), with 65.1% using their cellphone to send and receive email and 60.3% to access the Internet. Forty-one percent owned a laptop computer and one-quarter a desktop computer. Seventy-four percent used one of their personal electronic devices to access the Internet. However, many of the women who did not have a personal electronic device used a friend's or relative's device, or a computer at the public library or CBO. The most common reasons for going online included reading or sending email (76.2%), accessing social networking sites (74.6%), and conducting an online search (73.0%). A majority of women reported being familiar with Internet-related computer terms (73.0%) and helping others who were learning to use the Internet (57.1%).

### Health-related Internet, cell phone, and social media use among Internet users

Slightly less than half (46.0%) of Internet users with a cell phone used it to look up medical information and 17.5% used it to track their health. Approximately half (47.6%) used social networking sites to obtain health information and 17.5% to start or join a health-related group (Table 3). About one-third of users (38.1%) read about someone's health experience online and more than half (58.7%) watched an online video about a health-related issue. In comparison, fewer (15% or less) posted comments, questions, or information on online discussion groups, blogs, social networking sites, or health-related websites. Almost half (47.6%) reported ever being helped by following medical advice found online. Most participants reported knowing what Internet-based health resources were available (81.0%), and how to use the Internet to answer their own health-related questions (73.0%).

### Reasons for not using the Internet

Among Internet non-users, about one-quarter (27.5%) had someone in their household who currently used the Internet at home. Sixty percent of non-users were interested in using the Internet and 69.7% had asked a friend or family member to look something up or complete a task on the Internet for them. The main reasons for not using the Internet were lack of access to a computer or the Internet (37.5%) and not having the skills to use the Internet (37.5%). Only 20% reported that they had no interest in using the Internet.

### Differences between Internet users and Internet non-users

Compared with Internet non-users, Internet users were more likely to be younger (median 49 [IQR 44–54] vs. 52 [IQR 47–58] years old,  $p < 0.05$ ), have a high school education or greater (61.3% vs. 40.0%,  $p < 0.05$ ), be stably housed (65.1% vs. 35.0%,  $p < 0.01$ ), be a primary caregiver (41.3% vs. 15.0%,  $p < 0.01$ ), go to a health center or clinic for HIV medical care (93.7% vs. 76.9%,  $p < 0.05$ ) and to report low health-related social support (54.0% vs. 32.5%,  $p < 0.05$ ) (Table 1). However, Internet-using women were less likely to have a chronic medical condition other than HIV infection (69.8% vs. 87.5%,  $p < 0.05$ ).

### Discussion

We sought to describe the patterns of Internet use for general and health-related purposes among HIV-positive women and to explore differences in characteristics between Internet users and non-users. Results showed that most (61%) women were current Internet users, the majority of whom had a personal electronic device which they used to access the Internet. Although higher proportions of Internet users were passively engaged (e.g., reading information or watching videos for health-related purposes), a sizable minority of women were involved in more interactive activities such as posting comments, questions, or information about health-related issues. A majority of non-users expressed interest in going online, but noted their lack of Internet access and navigation skills as the primary reasons for non-use. Compared with Internet non-users, current Internet users were more likely to be younger, have higher socio-economic status, and to report low health-related social support.

Our study findings contribute to the growing literature about Internet use among HIV-positive persons. Prior studies have not examined patterns of Internet use among HIV-positive women and most have not examined current Internet use among HIV-positive persons, instead focusing on “ever use” (Kalichman et al., 2003; Mayben & Giordano, 2007; Thomas & Shuter, 2010). We found that 61% of women in our sample were current Internet users, which is similar to “ever use” estimates in these prior studies, but lower than the proportion of current Internet users in the general US population (86%) (Brenner & Smith, 2013). Age and socioeconomic status (e.g., education, housing) were associated with Internet use, similar to findings from previous studies (Kalichman et al., 2003; Mayben & Giordano, 2007; Thomas & Shuter, 2010). Although an earlier study found Internet health-seeking to be positively associated with social support, our study found Internet use to be negatively associated with health-related social support (Kalichman et al., 2003). These divergent findings may be the result of differences in measurement (current vs. ever Internet use), in sampling (recruiting women only vs. men and women), or variable definitions (general social support vs. health-related social support).

Despite having a lower proportion of current Internet users as compared with the general population, Internet-using women in this study had a high level of online engagement. Of Internet users, two-thirds reported going online at least 3–5 times per week and almost three-quarters used social networking sites. Although we did not formally compare differences between our sample and the general population, we found women in our study were more likely to use the Internet for health-related purposes than the general population (Fox & Duggan, 2013). For instance, while 43% of Internet users in our study signed up to receive



an email update about health issues, only 11% of those in the general population did (Fox & Duggan, 2013). Additionally, the proportions actively involved in posting health-related content (13–16%) in our study were higher than the general population (4–8%; Fox, 2011). Overall, these data suggest that fewer HIV-positive women may access the Internet, however, once online, they actively engage and participate in health-enhancing behaviors online.

These findings have implications for the development of Internet-based interventions for HIV-positive women. The low rates of Internet use among women in our sample and the limited digital access and literacy reported by some women suggest that barriers exist for implementing online interventions for this population. However, it is encouraging that many non-users expressed interest in using the Internet. Therefore, to address issues of computer or Internet access, interventions targeting HIV-positive women may need to provide access to mobile devices or computers and/or expand Internet access at CBOs and clinics. To improve Internet navigation skills, interventions should integrate online training modules as an essential component of the intervention as a few previous Internet interventions have successfully done (Kalichman, Weinhardt, Benotsch, & Cherry, 2002; Kalichman et al., 2006).

We identified potentially important differences between Internet users and non-users that may be important to consider in the design of future Internet-based interventions focused on HIV-positive women. As Internet users in our study were younger and had a higher level of socioeconomic status than non-users on several measures, women with these characteristics may be easier to recruit for Internet-based interventions. It also further highlights potential challenges in engaging older women and those with fewer socioeconomic resources in such interventions. Compared with non-users, we found that Internet users were more likely to report low health-related social support. This may suggest that women without substantial social support are seeking support online. Prior research has shown that HIV-positive women often lack positive social support (Hosek, Brothers, & Lemos, 2012; Squires et al., 2011; Walsh, Horvath, Fisher, & Courtenay-Quirk, 2012) and that recently diagnosed women, particularly, may go online to identify support resources (Walsh et al., 2012). Although, the comparisons did not reach statistical significance, we also found that Internet users were more likely to report antiretro-viral nonadherence and high HIV-related stigma. These findings, which merit further study, may indicate that Internet-based interventions (e.g., an online group) for HIV-positive women may be well-positioned to provide social support which may, in turn, lessen stigma and help promote positive behavior change, such as improved adherence.

Our study has several limitations. First, we used a convenience sample of women from Bronx-based CBOs which limits the generalizability of our findings to HIV-positive women in other regions of the USA. However, as one of the first to report on Internet use practices of HIV-positive women, this study fills an important gap in the literature. Second, our definition of “Internet user” was based on a single item and may not fully capture nuances in Internet engagement. However, as this definition has been used in nationally representative surveys of US adults, we were able to draw direct comparisons between Internet use among

this sample of women and Internet use among US adults. Third, we did not ask participants specifically about Internet use for obtaining information or communicating about HIV.

The Internet is being adopted among all segments of the US population, including HIV-positive women. Internet-using women in our study showed relatively high levels of engagement and participation. Most non-users were interested in learning to use the Internet. As such, it is imperative to consider how to most effectively roll out Internet-based interventions to HIV-positive women to improve health behaviors and, ultimately, health outcomes.

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**Table 1**

Participant socio-demographic, clinical, and risk behavior characteristics for the overall sample and by internet use status ( $n = 103$ ).

	<b>Total sample <math>n = 103</math></b>	<b>Internet users <math>n = 63</math></b>	<b>Internet Non-users <math>n = 40</math></b>	<b><i>p</i></b>
Age (years), median, (IQR)	50 (45–54)	49 (44–54)	52 (47–58)	0.02
Race/ethnicity, $n$ (%)				0.74
Non-Hispanic Black	59 (59.6%)	34 (56.7%)	25 (64.1%)	
Hispanic	35 (35.4%)	23 (38.3%)	12 (30.8%)	
Multiracial/Other	5 (5.0%)	3 (5.0%)	2 (5.1%)	
Relationship status, single, $n$ (%)	61 (59.2%)	36 (66.7%)	25 (71.4%)	0.63
Less than high school education, $n$ (%)	48 (46.6%)	24 (38.7%)	24 (60.0%)	0.04
Income less than \$10,000/year, $n$ (%)	75 (72.8%)	45 (79.0%)	30 (93.8%)	0.07
Unstably housed, $n$ (%)	48 (46.6%)	22 (34.9%)	26 (65.0%)	0.003
Primary caregiver, $n$ (%)	32 (31.1%)	26 (41.3%)	6 (15.0%)	0.005
Lack of health insurance, $n$ (%)	8 (7.8%)	3 (4.8%)	5 (12.5%)	0.15
Current high-risk sexual behaviors, $n$ (%)	41 (39.8%)	27 (42.9%)	14 (35.0%)	0.42
Recent substance use	40 (38.3%)	24 (38.1%)	16 (40.0%)	0.84
Fair/poor health status, $n$ (%)	24 (23.3%)	15 (24.2%)	8 (20.0%)	0.62
Depression, $n$ (%)	39 (37.9%)	24 (38.1%)	15 (37.5%)	0.95
Chronic medical condition, $n$ (%)	79 (76.7%)	44 (69.8%)	35 (87.5%)	0.04
Time since HIV diagnosis (years), median (IQR)	17 (11–23)	15 (9–23)	18 (14–24)	0.16
Place of HIV medical care, $n$ (%)				0.01
Health center/clinic/private PCP	89 (87.3%)	59 (93.7%)	30 (76.9%)	
HC for homeless/MMTP/visiting PCP	13 (12.8%)	4 (6.3%)	9 (23.1%)	
1 HIV medical care visit in last 6 months, $n$ (%)	96 (93.2%)	61 (96.9%)	35 (87.5%)	0.07
Prescribed antiretroviral medications, $n$ (%)	92 (89.3%)	54 (85.7%)	38 (95.0%)	0.07
Nonadherent to antiretrovirals, $n$ (%)	29 (31.9%)	21 (39.6%)	8 (21.1%)	0.06
High HIV-related stigma, $n$ (%)	–	39 (61.9%)	18 (45.0%)	0.09
Low health-related social support, $n$ (%)	–	34 (54.0%)	13 (32.5%)	0.03

Note: Nonadherent defined as reporting taking less than 100% of antiretrovirals in the last 30 days. HIV-related stigma (low vs. high) and health-related social support (low vs. high) were dichotomized at the median split. Percentages represent column percentages.

IQR, interquartile range; PCP, primary care provider; HC, health care; MMTP, methadone maintenance treatment program.

**Table 2**Internet, cell phone, and social media use among Internet users ( $n = 63$ ).

	<i>n</i> (%)
Frequency of Internet/email	
Daily	29 (46.0)
3–5 days a week	11 (17.5)
Once a week	6 (9.5)
Every few weeks	7 (11.1)
Less often	10 (15.9)
Own a desktop computer	18 (28.6)
Own a laptop computer or notebook	26 (41.3)
Own Cellphone/smartphone	55 (87.3)
Use to send or receive email	41 (65.1)
Use to send or receive texts	53 (84.1)
Use to access the Internet	38 (60.3)
Use to participate in video chat	22 (34.9)
Own electronic book device/ebook	6 (9.5)
Own tablet computer (e.g., iPad)	18 (28.6)
Uses personal electronic device to go on the Internet	47 (74.6)
Internet to read/send email	48 (76.2)
Emailed yesterday	27 (42.9)
Internet to search online	46 (73.0)
Searched online yesterday	35 (39.7)
Internet to take part in chat rooms or online discussions	18 (28.6)
Chat rooms yesterday	10 (15.9)
Internet to pay to access or download digital content	33 (52.4)
Downloaded digital content yesterday	15 (23.8)
Internet to use social media networking sites	47 (74.6)
Social media yesterday	31 (49.2)
Internet for Twitter	25 (39.7)
Twitter yesterday	18 (28.6)
Internet for video chat	18 (28.6)
Video chat yesterday	9 (14.3)
Internet for sharing pictures	24 (38.1)
Sharing pictures yesterday	16 (25.4)
Internet knowledge	
Can understand most Internet-related computer terms	46 (73.0)
Can usually fix problem encountered when using the Internet	34 (54.0)
Helps others who are learning to use the Internet	36 (57.1)
Has changed settings preferences on own computer related to Internet access	26 (41.3)

**Table 3**Internet and social media use for health-related information and communication ( $n = 63$ ).

	<i>n</i> (%)
Own cellphone/smartphone	
Use to track health	11 (17.5)
Use to look up medical information	29 (46.0)
Used social networking sites	
To get health info	30 (47.6)
To start or join a health-related group	11 (17.5)
To follow your friends' health updates	20 (31.8)
Signed up to receive email updates about health or medical issues	27 (42.9)
Read someone's health experience about health or medical issues online	24 (38.1)
Watched an online video about health or medical issues	37 (58.7)
Gone online to find others who might have similar health concerns	29 (46.0)
Posted comments, questions, or information about health or medical issues:	
in an online discussion, a listserv or other online group forum	10 (15.9)
in a blog	8 (12.7)
on a social networking site such as Facebook, LinkedIn, or Google Plus	10 (15.9)
on Twitter or another status update site	9 (14.3)
on a website of any kind, such as a health site or news site that allows comments and discussion	10 (15.9)
Ever helped by following medical advice or health info on the Internet	30 (47.6)
Ever harmed by following medical advice or health info on the Internet	9 (14.3)
Electronic health literacy	
Know <i>what</i> health resources are available on the Internet	51 (81.0)
Know <i>where</i> to find helpful health resources on the Internet	44 (69.8)
Know <i>how</i> to find helpful health resources on the Internet	44 (69.8)
Know <i>how</i> to use the Internet to answer own questions about health	16 (25.4)
Know <i>how</i> to use health information on the Internet to help me	45 (71.4)
Have the skills needed to evaluate health resources on the Internet	44 (68.8)
Can tell high quality from low quality health resources on the Internet	27 (42.9)
Feel confident in using information from the Internet to make health decisions	37 (58.7)